

GENETICS AND SOCIAL POLICY*

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FOR SEVERAL YEARS, philosophers, sociologists, and policy analysts have been trying to explore the social, legal, and ethical implications of the tests that will emerge from the Human Genome Project. Except for prenatal screening, genetic tests are not yet very widely employed. What can one actually study that would allow some fairly concrete prediction of how these technologies—as they become available—will actually be used? In writing our book, *Dangerous Diagnostics; The Social Power of Biological Information*,¹ Laurence Tancredi and I struggled over this question. Two approaches seemed reasonable. First, new technologies need to be socially acceptable. What cultural predispositions might suggest how predictive testing will be used in acceptable ways? This is, I believe, a critical question and is the topic of my current research. Second, technologies are mediated through social institutions. On the basis of existing institutional practices and needs, how can we expect predictive genetic tests to be employed? Third, in light of considerable past experience with other kinds of tests, what can we anticipate will be the implications of the growing use of genetic tests?

CULTURAL PREDISPOSITIONS

The preoccupation with testing in American society reflects two cultural tendencies: an actuarial mind-set evident in our prevailing approach to problems of potential risk and a related tendency to reduce problems to biological or medical terms. Actuarial thinking is designed to limit liability. It places value on weighing costs and benefits and developing quantitative means of planning and prediction so as to minimize risk. Controlling risk requires calculating the cost of future contingencies, taking into account expected

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losses and selecting good risks while excluding bad ones. To do so it is necessary to understand the individual actuarially, that is, as part of a statistical aggregate.

The actuarial mentality thrives on information about the health, habits, and behavior of individuals. Accumulation of data is thus an important feature of every organization, and testing is part of this trend. Nothing indicates popular support more clearly than a market. There is demand for testing, so much so that in anticipation of a market for testing, several biotech firms are in the business of collecting blood samples for future genetic tests as they become available. Faith in facts and in numbers derived from tests has frequently obscured the uncertainties intrinsic to most tests—for drugs, for IQ—and tests are widely viewed as neutral, necessary, and benign.

If faith in facts is part of the actuarial mentality, so too is the tendency to reduce social problems to measurable biological or medical dimensions. We routinely use medical judgments to define the boundaries of “normal” behavior and thereby to identify competence, deviance, or capacity to work. Biological reductionism has evolved from the tendency to medicalize social problems. In its contemporary manifestation, medicalization has incorporated notions of biological fitness or perfectibility, and the idea that these are matters of personal choice. It is assumed that there exists an ideal of normality or perfection against which individuals can be measured, that complex human behavior can be reduced to biological or genetic explanations, and that behavioral problems can be attributed to biological determinants with minimal reference to social or environmental influences.

The media have been quick to respond to these ideas. Covering the Baby M case, a story in *U.S. News and World Report*² proclaimed that “solid evidence demonstrates that our very character is molded by heredity.” The article, therefore, questioned whether Baby M’s future really hinged on which family would bring her up. In tracing the genetic themes in popular culture, I am finding these themes expressed in several ways—a pervasive emphasis on the critical importance of preserving genetic relationships; a persistent notion that biology is destiny, that all traits, behavioral as well as physical, are genetically predetermined; a growing preoccupation with identifying the genetic characteristics of specific groups (mainly women and blacks); and even a fear that the human species is threatened with evolutionary decline. The media coverage of sociobiology, the appeal of the Bouchard twin studies, the popularity of genealogies and the search for roots, the remarkable media interest in studies of the genetic basis of alcoholism and crime, all suggest a culture predisposed to accept genetic explanations.

A great deal has been written about the social policy implications of biological determinism in the late 19th and early 20th centuries. Less has been said about the reemergence of genetic explanations in more recent cultural discourse. Scientists themselves, encouraged by recent advances, have expounded on the social meanings inherent in their work, and on applications of genetic understanding to social policy. Geneticist Marjorie Shaw has asserted that "the law must control the spread of genes causing severe deleterious effects, just as disabling pathogenic bacteria and viruses are controlled."³ Dan Koshland, editor of *Science*, writes that "In the warfare between nature and nurture, nature has clearly won."⁴ Others refer to "pollution of the human gene pool," "genetically healthy societies," or "optimal genetic strategies" to predict and therefore control genetic health.

Both the scientific and popular discourse focuses increasingly on the importance of genetics in predicting behavior and health. This discourse, in effect, reduces the body to a machine-like system permeable to visualization and understandable by deciphering a code. It provides a theoretical structure to explain human behavior and a justification for a growing use of genetic tests in a range of social institutions, including schools, workplaces, and the courts.

INSTITUTIONAL USE OF TESTS

Diagnostic tools obviously serve many useful and humane purposes: they identify potential health problems for therapeutic or preventive action. In nonclinical contexts, tests are used to channel learning disabled children into appropriate educational channels, to protect vulnerable workers from exposure to toxic substances, to provide solid evidence for legal decisions. We also know, however, that diagnostic tools can be abused; that testing has frequently served to justify racial or gender biases, to legitimate exclusionary practices, or to enhance institutional power and control with little regard for the rights of individuals.

The prerogative to test has long been recognized as a source of institutional power. Foucault saw the examination as a strategy of political domination, a means of "normalization." In *Discipline and Punish* he described the examination as "a normalizing gaze, that introduces the constraints of conformity . . . that compares, differentiates, hierarchizes, excludes." Foucault also observed the extension of testing throughout the society. "The judges of normality are present everywhere. We are a society of the teacher-judge, the educator-judge, the social worker-judge. . . we are entering the age of the infinite examination and of compulsory objectification."

Foucault wrote of pedagogical tests.⁵ Others, such as Walter Reich,⁶ have developed a similar analysis of the role of psychiatric tests to reinforce political hierarchies and social values. Similarly, anthropologists have long described the way cultures employ nature to support the ongoing social system. As Mary Douglas put it:⁷ "Institutions bestow sameness. . . . They trim the body's shape to their conventions." In our society as well, we call upon nature by using biological tests to assure that individuals conform to institutional values. In some cases, institutions exercise control through force, but most often they control their constituents by symbolic manipulation. Sanctioned by scientific authority and implemented by medical professionals, tests are an effective means of manipulation; for they imply that decisions are implemented for the good of the individual. They are, therefore, a powerful tool in shaping individual choices in ways that conform to institutional values.

Schools, employers, insurers, the courts all stand to gain from better understanding of the present and future health status and behavioral syndromes of their clients. In these settings economic constraints and administrative pressures for accountability enhance the appeal of tests that can uncover latent conditions and predict the future health or behavior of their client populations. Let me briefly explore how tests are used by such institutions to meet their economic and political needs.

First of all, with their aura of scientific objectivity, biology-based tests are a means to redefine problematic behavior in individuals in ways that protect routine practices. Public schools, for example, have faced consistent criticism from government and advocacy groups because of educational failures. In particular, they must explain the large number of middle class children who have academic difficulties but normal IQs and no obvious hearing or visual loss. In the late 1960s the category of "learning disabled" came into common use, replacing such labels as "emotionally disturbed," "culturally deprived," or "nutritionally deficient," even as "working mother's syndrome." With the help of diagnostic tests, several million school children have since been diagnosed as learning disabled. Some suggest that one in 10 children are undiscovered victims of "minimal neural dysfunctions" or "minimal brain disorders" that affect their performance in school.

Behavioral problems, once explained in terms of environmental or social influences, are also attributed to the biology of the child. Hyperactivity, at one time a problem in classroom dynamics, has been redefined as "attention deficit disorder," a problem located in the students' brain. The behavioral or learning difficulties of such children are, of course, real. But the new labels

are also an institutional convenience, removing blame from schools, families, or other social influences.

These biological explanations of learning difficulties have both reflected and encouraged the use of diagnostic tests that can identify small differences in brain activity among children. These include electroencephalograms, neuropsychological tests, genetic analyses, and left-right brain lateralization tests. Some are expected to predict at an early age children likely to be slow learners, dyslexic, or disruptive during their school years. With refinement in testing, the numbers of children classified as disabled has more than doubled during the past decade.

Second, the predictive capacity of biological tests is also useful to organizations as a means to facilitate long-term planning in a context of growing cost containment pressures. Prediction and planning are, of course, important to all organizations but let us focus on the health care system. The economics and efficiency of treatment decisions is increasingly urgent in light of the growing number of prepaid medical plans and the financial dilemmas of insurance companies. Pressure for efficiency also comes from government policies linking Medicaid reimbursement to diagnostic categories. These pressures, along with the ubiquitous threat of litigation, create powerful incentives to back up health care decisions with objective and predictive evidence. They encourage competition for "profitable" patients, people who carry no dangerous genetic characteristics and who have predictable and reimbursable illnesses. Diagnostic tests facilitate the process of categorizing patients; they provide technical evidence to support complicated or controversial decisions, and they provide the patient profiles necessary to control access to health care facilities or to plan for future institutional demands.

Genetic disorders are believed to account for 20 to 30% of all live births and 12% of all hospital admissions in the United States. At present about 31 to 37 million people in the United States have no health insurance. About 15% of those insured are individually covered and must meet underwriting standards by providing their health histories, information on their family illnesses, and evidence of their current state of health to obtain insurance. Sometimes tests are required. According to a survey by the Office of Technology Assessment, in 1987 20% of these individual applicants were issued policies that excluded pre-existing conditions or paid higher premiums; 8% were denied coverage for diseases including obesity, alcoholism, cancer, schizophrenia, and AIDS. Health Maintenance Organizations denied membership to 24% of individual applicants. Those with "bad" genetic markers may simply be added to the growing number of people without access to medical coverage.

A third source of the appeal of genetic testing follows from its promise of enhancing institutional efficiency. As employers increasingly assume responsibility as insurers or health care providers, biological tests have become a means to justify the exclusion of high risk individuals from work. The predisposition to use testing as a means of exclusion from work is well established. In 1985 49% of American employers required pre-employment medical examinations, a 10% increase since the early 1970s. Pre-employment examinations include various predictive tests ranging from psychological tests for future executives to lower back roentgenograms for construction workers. Even dubious diagnostic procedures persist. About one million pre-employment roentgenograms are taken on asymptomatic individuals despite evidence that only 2% of those screened out ever develop serious back trouble. Faced by regulatory pressures and litigation and concerned about absenteeism and illness, chemical companies have used genetic screening techniques to predict and exclude employees susceptible of being genetically predisposed to illness from exposure to chemicals. Justified in the first instance as a way to protect worker health, genetic tests can be used to avoid making costly changes in the workplace environment. But they have also operated to exclude not only specific individuals, but certain groups.

Recent debates over fetal protection policies have highlighted problems involved in such practices. Yet, in the context of growing economic competition, employers view screening techniques that will identify those predisposed to genetic disease as a cost-effective way to control absenteeism, reduce compensation claims and debilitating lawsuits, and avoid future medical costs. While politically charged, the use of tests that facilitate the selection and maintenance of a productive low risk work force is simply rational economic policy. Greater certainty in testing is expected to mute political opposition.

Finally, organizations use tests to provide hard evidence that can justify or guide ambiguous decisions about those who will not or cannot conform. In hospital, tests can define an uncooperative patient as biologically incompetent, unable to make autonomous decisions, and in need of paternalistic control. And in face of disaffection with psychiatric evidence underlying the insanity defense, the courts are predisposed to adopt biological tests that can provide "hard" facts—that is, a more objective scientific basis—on which to make decisions about the responsibility and disposition of defendants.

Grounded in science, genetic tests will be compelling; and their limits are likely to be ignored. The tendency, certainly in the popular press, is to talk about all genetic tests as if they were predicting rather simple single gene

disorders, ignoring that in most diseases the manifestation of symptoms, their severity, and when they will appear rest on the interaction of multiple genes and on intervening factors—diet, lifestyle, or the influence of environmental or social interactions.

IMPLICATIONS

Let me conclude by anticipating some consequences of the growing availability of genetic tests. The refinement of tests, the ability to detect small deviations from the normal, expands the number of disease categories and the number of people judged deviant or abnormal. Those identified as disabled and excluded from insurance and prepaid health plans are growing. Genetic testing, in the context of the expectations of insurers for full information, will add to those uninsurable.

Furthermore, expansion of testing and concomitant belief in the biological causes of disease is likely to enhance the role of medical experts in nonclinical settings. Physicians have long interacted with other institutions to assist in and legitimize social policy. They interact with the law by reporting venereal disease or gunshot wounds, with schools by evaluating absenteeism or learning disabilities, with industry by judging responsibility for accidents or illness, or the ability to perform certain jobs, with the military by authorizing deferments, with the courts by determining the mental status and moral responsibility of criminals and their competency to stand trial. Ability to provide more reliable characterizations of physical and psychological disorders gives greater power to medical professionals—the company doctor, the school psychologist, the forensic psychiatrist. Because of their conflicting interests these professionals welcome testing as a neutral data base to justify controversial decisions. But such tests may further complicate their already ambiguous roles.

Expansion of genetic testing also implies certain therapeutic options. On the one hand this can be useful to patients; tests can help to assess the effectiveness of specific therapies. On the other hand, the use of tests to evaluate behavioral problems has already encouraged extensive use of drugs such as Ritalin® for school children, and shifted the focus from social influences on their behavior. Moreover, as tests become more refined, professionals may rely more on test results than on symptoms of individuals. In the context of malpractice litigation, credibility—provided by tests—may prevail over validity, especially in cases of potential conflict.

Finally, predictive screening opens possibilities for biological discrimination and state control. At present, prenatal genetic screening is used to expand

the reproductive options of the family. Choices are theoretically left to the discretion of individuals. This, however, does not rule out professional or state control over reproductive decisions. State chromosomal registries are demanding more information on birth defects from genetic laboratories. There are precedents for state intervention. It was not so long ago that some states provided for the sterilization of the mentally retarded and seriously psychotically ill. In 1976 the Supreme Court of North Carolina ruled that the State had a right to “prevent the procreation of children who will become a burden on the state.”

The possibilities for discrimination are evident. Tarasoff-like arguments about compelling social interest have been used to support compulsory genetic testing of high risk people and informing family members. Data banks are proliferating—some for crime detection, but others for screening disease. Vivigen, a biotech lab, has a genetic repository for people who want to bank their DNA so it will be available when there are linkage tests. The caveats in their contracts suggest that questions of medical confidentiality are not resolved.

Cases of genetic discrimination are proliferating; people who are asymptomatic but suspected of having a genetic disease have been barred from insurance, drivers’ licenses, or employment because of their genetic labels. In one publicized case, an insurer warned a woman whose fetus tested positive for cystic fibrosis that she would not receive medical coverage for the child if it were born with the disease. One can imagine families demanding information about their genetic roots or commercial firms selling genetic information to such interested agencies as insurers.

Questions of access to test results will juxtapose the privacy of individuals against the interests of relations and employers. Do members of a family have a right to information about the biological status of their relations? Should a physician have the right or obligation to communicate information about genetic disease to family members who may be similarly afflicted? Should people seeking to adopt a child be able to probe the genetic history of those children available to shop for an appropriate match? Can the right to be employed depend on having the right genes?

The significance of biological information rests, of course, on just how it will be used. But it is clear that many groups have strong interests in the biological condition of those in their domain, including Departments of Motor Vehicles, immigration authorities, creditors, professional sports teams, the military, and even university tenure committees.

As Foucault observed,⁸ tests that establish statistical standards of normal behavior against which to measure individuals have long been used to measure competence, to define deviance, to exclude, to define those who are more or less worthy or desirable. Technologies that tap into biological understanding about how the body functions and how it can be expected to function during the course of an individual's life are but an extension of earlier pedagogical and psychiatric tests. But they have greater credibility as assumptions of neutrality conceal the values embedded in technological findings and the specificity of tests mute moral reservations about privacy, personhood, or individual rights. Considering the rapid development of diagnostic technologies, there has been little discussion about the employment of tests in such nonmedical contexts, about the critical questions of access to biological information, and the need to avoid abuse.

Diagnosis remains an uncertain art. But even as tests increase in accuracy and expand the range of what they can predict, key questions of interpretation will remain. What degree of correlation between existing markers and subsequent physical or behavioral manifestations is necessary before taking social action such as exclusion from work, tracking in special educational programs, establishing competency to stand trial? How do we balance an organization's need for stability and the rights of individuals? What is to be defined as normal or abnormal and whose yardstick should prevail? Perhaps most important, even if there were to be perfect predictive information, can we afford policies that further expand the number of people who are unemployed and uninsurable? Can we afford a genetic underclass?

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